Facing Dementia: The Social Psychiatry Perspective

THEOFANIS VORVOLAKOS*

Abstract

Dementia is a major public health issue. Scientists from many different disciplines are making progress in understanding and treating dementia. Social psychiatry principles can be applied effectively in order to deliver proper care as well as to set the strategic goals of dealing with it.

Major goals are: early diagnosis of dementia, adequate support of patients and their carers, measures to improve patient's quality of life until their final stages research control and proper administration of all the services that are involved in this procedure. Models of delivery of care in order to serve these goals like raising in general public awareness as well as designing services in primary secondary and palliative care are also suggested with in the context of Social Psychiatry approach.

Research data suggest that these approaches are both cost effective and efficacious in improving quality of life and decreasing the frequency and seriousness of complications in people suffering from dementia.

Key words: dementia, social psychiatry

Introduction

Dementia is considered by many an ongoing major medical and social challenge. Thanks to neurosciences lots of information is available regarding the pathophysiology, phenomenology, course and prognosis of dementia. There are significant problems though regarding the transfer of all this knowledge in every day clinical practice. Social psychiatry plays a major role in the application of this knowledge.

United Kingdom through the various NHS and local authorities' services implements a dynamic model dur-

*Psychiatrist Senior Lecturer Psychiatry Department Democritus University of Thrace ing last years that tries to combine modern knowledge with clinical practice in a cost effective manner. Although no one can claim that this is the best or the only available model it is true that this is a dynamic and constantly revisable model.

In 2006 the National Institute of Clinical Excellence issued the Dementia guidelines. This was followed in 2008 by the National Strategy of Dementia and in 2011 the Good Practice Compendium was issued.

Dementia strategy included 18 different goals regarding dementia treatment. These goals can be divided in four different categories:

- 1) Early diagnosis of dementia,
- 2) Adequate support of patients and their carers
- 3) Measures to improve patient's quality of life until their final stages
- 4) Research control and proper administration of all the services that are involved in this procedure.

Major Goals of Social Psychiatry Approach

Early diagnosis and public awareness

There is an increase need to achieve this goal since Dementia is grossly under diagnosed often until it becomes moderate to severe. In order to deal with this phainomenon public awareness and understanding of Dementia must be improved. There must be enough high quality information available for the public in order for them to be able to detect early signs of the disorder as soon as it is possible. There is also a similar issue regarding health care professionals in order for them to have a high degree of clinical suspicion regarding memory complain from the general public.

Accurate and early diagnosis of dementia is important also. There is an increasing need for early diagnosis. This is important because early interventions in dementia even mild ones are much more important and sustainable than late interventions even if they are much more intensive. Despite that knowledge though

in many cases patients, carers and professionals tend to wait for mild dementia to become severe in order for them to intervene.

Adequate and qualitative support regarding patients and their cares

Patients must also be supported by social networks and peer groups in order for them to preserve as much as it is possible their social support, this includes access to high quality care, support and information after receiving the dementia diagnosis.

Dementia is a difficult to treat and complicated disease regarding its symptoms, its progression and patient needs. Both patients and their cares must feel empowered to deal with dementia. Facts regarding disease must be explained in an understandable and client friendly manner. There must also be additional access to high quality information in order for people to be able to make or to suggest alternative approaches for the various issues regarding the dementia. Efforts can be made to respect and to incorporate these views in the care packages. Some times it is difficult but other times like par example, helping a patient suffering from dementia attending to church, can be easier.

Carers are as important as patients in dealing with dementia. So their needs must be addressed also as a separate goal. Support networks like the ones described for patients can give them significant social support. This approach also has a direct effect to patients since they tent to feel much better if they understand that their carers are well supported physically, financially and mentally.

Improving quality of life until the late stages of the disease

Dementia is a progressive and degenerative disease. It is necessary to improve the quality of life for these patients and also to discuss and prepare for the late stages of the disease that are also the most challenging ones. In the late stages of the disease there is no available medication for the main symptoms thus social interventions are of great importance.

The most crucial issues that need to be addressed are the following:

A) Improvement of quality of life everywhere the demented patients might be. The main way to achieve

this is for the professionals involved to high consideration of their special medical and care needs in hospitals, hostels, nursing houses as well as day centres and day hospitals.

In many cases special needs or common medical complications associated with dementia are either ignored or considered normal and worthless of treatment despite the fact that can be serious. The most common example is delirium that is very often associated with dementia and still is underdiagnosed as well as under or mistreated. Another issue is the fact the people suffering from dementia have great difficulties in communicating their needs. All these must be taken into account by the health professionals in any facility that patients suffering from dementia attend.

- **B)** Extensive use of technology like telecare can be applied, since this can be cost effective and efficacious allowing better utilization of resources while at the same time it is less restrictive serving the principals of social psychiatry.
- **C)** Proper planning and preparation for the end of life. This is a taboo issue but it's quite crucial for the patients as well as for the cares. Improper use of medicine or medical practices or unnecessary hospitalizations is common during the end stages of the disease and is quite inhumane and stressful for the cares as well as the patient.
- **D)** Regarding quality of life in people with dementia a special reference to the use of antipsychotics must be made. Despite the fact that they are extensively used for behavioural control of people with dementia their benefits are controversial. On the other hand there is not much debate regarding the side effects of their use, like threefold increase likelihood of a stroke, twofold increase possibility of death, increase of falls, decrease of quality of life, doubling the rate of cognitive decline, increases the possibility of metabolic syndrome and on top of all these rare discontinuation of the antipsychotics even when they are no longer necessary.

If we take into account the pros and cons of their use as well as the evidence based practice it is obvious that their use should be avoided as much as it is possible. This makes much more important the early diagnosis and the proper planning for the disease in order to avoid for as long as it is possible behavioural problems.

Control Research and Planning

Main issue regarding application of social psychiatry practices in dementia is that dementia is a complicated disease. Many services and many people tend to be involved ranging in a spectrum from social care services to legal administration. There are great needs for coordination between them in the local level as well as in national level.

In order to make the proper planning in national level there is the need for high quality research. This is the main way to design sustainable cost effective and adequate services. There is also constant need for training for the professionals that are involved and also monitoring of the outcome of every intervantion.

These are difficult but crucial issues that must be resolved other wise everything can and will fail.

Models of care

Although the theory of social approach was presented above it will remain theory if there are no suggestions about the models of delivery of care. There are many models available and all can be applied depending on the needs the available resources and cultural or other differences.

Public awareness

Raising public awareness is probably the most crucial issue. Use of every available approach is quite useful. Symposiums, courses, psycho educational groups can be used as well as mass media, internet and last but not least religious leaders can play an important role increasing peoples awareness about memory issues.

Primary Care

In primary care, constant training of the personnel as well as appropriate and simple to use screening tools can be used in order for them to able to detect dementias in their early stages and refer them in the secondary care settings.

Dementia diagnosis should be avoided in primary care. So it is better for the referral threshold to be low in order to detect more often, but not over treat dementia. If dementia is, as many consider, 21st century can-

cer we must keep in mind that cancer is not diagnosed in a primary care setting. The same can be applied for dementia. In fact in UK during the last decade the percentage of dementias that are diagnosed in primary care decreased.

Secondary Care

There are many models of care regarding dementia in secondary care settings the most important is the community mental health team that make house visits or visits in nursing homes. This is a multidisciplinary team. Anyone well aware of dementia regardless of his background e.g. Neurologist or Psychiatrist can be the medical officer of such team but team must be multidisciplinary including psychologists, social workers, community nurses, occupational therapists etc. Other models of secondary care are memory clinics or liaison teams in general hospitals.

There is an increased risk of burn out syndrome for care coordinators in these settings especially the community mental health team. Certain bad outcome, necessity for palliative care at the end, constant decline of the patient as well as need for home calls in almost every case and the increased work burden since population is getting older are the most important stressors that makes this quite possible and every team must be able to deal with it.

Palliative Care

The issue of palliative care is also an important one since as we mentioned before it is certain that at some point the need for it will arise. There various legal and ethical issues about the obligation to resuscitate in this stage if need arises. There no easy answers and probably this is a legislation and not medical issue. But there are simpler issues. Hospitalization is better to be avoided as well as medication. Carers and professionals must be supported in these stages through protocols in order to be easier for them to make difficult choices. In cases that there are no alternatives ideally hospices are better than ordinary hospitals for the end stages of the disease.

Conclusion

Dementia is an important medical and social issue.

ENCEPHALOS 49, 55-59, 2012

Although research is mainly focused in neurophysiologicall aspects of the disease, treatment and complications management is often delivered through social services. Application of social psychiatry principles leads to better quality of life and fewer complications for people suffering from dementia from the early stages of the disease until the very late stages of it.

References

- Acton, G.J. &K'Kang J. (2001). Interventions to reduce the burden of care giving for an adult with dementia. A meta analysis. Research in Nursing and Health, 24(5), 349-360
- Adams, B et al. (2002). Ethnic and gender differences in distress among Anglo American, African American, Japanese American and Mexican American spoucal caregivers of persons with dementia. Journal of Clinical Geropsychology, 8(4), 279-301
- Burns, A & Rabins P. (2000). Carer burden in dementia.
 International Journal of Geriatric Psychiatry, 15, S9-S13
- 4. Canadian Study of Health and Aging (2000). The incidence of dementia in Canada. Neurology 55, 66-73
- Department of Health UK. (2011). A national Dementia Strategy, Good Practice Compendium an assets approach.
- 6. Garand L et al. (2002) A pilot study of immune and mood outcomes of a community-based intervention for dementia

- caregivers. Archives of Psychiatric Nursing, 16(4), 156-167
- Hopkins, R. W. & Hopkins J. F. (2002). Dementia projections for the countries, regional municipalities, and districts of Ontario. (Geriatric Psychiatry Programme. Clinical/Research Bulletin No 13) Kingston, Ontario PCCCC Mental Health Services
- Kabitsi N. & Powers D.V. (2002) Spousal motivation of care for demented older Adults. A cross cultural comparison of Greek and American Caregivers. Journal of Aging Studies 16 (4), 383-399
- Leon J. et al. (2000) Health related quality of life and service utilization in Alzheimer disease. A cross-sectional study.
 American Journal of Alzheimer's Disease, 15, 94-108
- Teel. S.C. & Carson, P. (2003). Family experiences in the journey through dementia, diagnosis and care. Journal of family Nursing, 9 (1), 38-58.